

## **SUMMARY**

### **NCBDDD External Partners Group Conference Call**

**Date:** Friday, March 12, 2004; **Time:** 1:00-2:30pm (EST)

**Next EPG Conference call: May 7 at 1:30 PM EST**

**Participants:** Clarke Ross, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD); Jane Correia, National Birth Defects Prevention Network (NBDPN); James Rimmer, National Center on Physical Activity & Disability (NCPAD); Barbara Kilbourne, National Center on Birth Defects and Developmental Disabilities (NCBDDD); Lowell Sever, Past Chair of EPG; Jeremy Scott, Tourette's Syndrome Association (TSA); Serena Lowe, B&D Sagamore; Maura Archambault, B&D Sagamore; George Jesien, Association of University Centers on Disabilities (AUCD) and Trista Sims (AUCD). Approximately 11 other people participated in the call as observers and were given the opportunity to make comments a number of times during the call. We apologize for those who were unable to participate on the call due to an inadvertent cap on the number of incoming lines with MCI. Additional lines will be secured for the next call.

#### ***Introductions and Overview of Agenda***

The conference call began at 1:30pm. Members of the Executive Committee followed by members of the larger Partners Group briefly introduced themselves, their organizations and their professional backgrounds.

George J. briefly described the format for the EPG conference calls again for those who were unable to participate on the last call. The EPG Executive Committee conference calls are open to the entire Partners Group. The format of these calls consist of the Executive Committee conducting the business meeting with opportunities for input from other Partner participants at specific times during the meeting, where appropriate, and with additional time for general comment and input toward the end of the call.

#### ***Update on the NCBDDD Strategic Planning Process/CDC Futures Initiative***

Barbara K. reported on the NCBDDD Strategic Planning process and the CDC Futures Initiative. Dr. Julie Gerberding, Director of the CDC, has requested the Futures Initiative report by the end of March. The report will consist of a lifespan model approach focusing on the five life stages: infancy, children, adolescence, adult and mature adult. The Infancy workgroup is chaired by Dr. Jose Cordero, NCBDDD Director.

NCBDDD and Booz-Allen-Hamilton (BAH) are still in the process of gaining feedback from the CDC staff and the EPG. Jim R. has taken the lead on developing a web-based format for the survey and will send a draft to the Executive Committee for feedback on the content and format of the questions. After the Executive Committee reviews and approves the survey, Jim R. will send out an email message via the Partners listserv with the URL for taking the survey. Jim plans to have the survey available **after March 22<sup>nd</sup>**.

The Partners Group will have approximately 2-3 weeks to complete the survey. The format of the survey is qualitative, open-ended, and consists of five core questions. The survey questions are as follows:

- What are the strengths of NCBDDD as an organization?
- What do you see as the key Center activities that should be prioritized during the next 5 years?
- What are the major challenges that NCBDDD will face over the next 5 years?
- What can the Center leadership do to ensure that NCBDDD is a successful center over the next 5 years?
- What can be done to improve the quality of your relationship with NCBDDD?

George J. suggested that it might be useful to considering including a quantitative portion to the survey using a likert scale to identify and rate specific areas. Jim R. has developed a similar survey, the Recreation Needs Survey (available at <http://www.rercrectech.org/surveys/default.htm>). He will draft some questions, as well as help in categorizing responses. Jim R. anticipates that this survey can be used over the next few years.

#### ***Update on National Public Health Week Activities – April 5-11, 2004***

##### **Hill Lunch Briefing**

Jeremy S., Serena L. and Maura A. have developed a 1-page proposal identifying the cost, invitees, date, as well as a letter of request for financial support to the Group for \$100 or more per organization. After reviewing the 1-page proposal, the Executive Committee decided to hold the Hill lunch briefing on **Thursday, April 8th** from 12-1:30pm at the House Resources Subcommittee Hearing Room, 1334 Longworth House Office Building, Washington D.C.

Congressional health staff with jurisdiction over or interest in the NCBDDD will be invited to attend. Staff from both the House and Senate will receive invitations. They will be briefed on the mission of the NCBDDD, its history, and the special populations it serves. Given the high staff turnover rate on the Hill, especially with the passage of the recent Medicare Modernization Act, many Congressional health staffers may be hearing about the Center for the first time at this briefing. The theme options for the briefing are as follows:

- Conduct a panel of four individuals (i.e., Dr. Jose Cordero) to speak on the overall purpose and goals of the NCBDDD and possibly EPG members that are affiliated with the Divisions can talk about specific topics.
- Each Division could highlight specific issues that are of current interest on the Hill (i.e., folic acid, newborn/childhood DD screening, prevention of secondary disabilities) and invite individuals who have directly benefited from the work of NCBDDD.
- Focus on the future of the NCBDDD (and have the leadership provide a brief description of its Strategic Initiative).

A number of comments were made regarding keeping the panel to a small number of speakers- no more than 3-4. It was suggested that a combination of themes should be taken into consideration. Lowell S. suggested that the briefing should focus on where the Center is at and where it needs to go (theme #1 & #3). Jeremy S. suggested that it would be beneficial to discuss a specific issue and how the Center addresses it (theme #1 & #2). Serena L. highlighted the importance of selecting the best speakers that can really break down programmatic activities so they appear interesting and pertinent to new Hill staff. For example, she suggested that a broad overview be provided with case studies on specific topics. Also, she explained that Hill staffers care about what goes on in their districts and providing state-specific information would be particularly appealing. She is willing to work on synthesizing this information to make it more succinct and to focus on the overall message, so that it's useful for Hill staff.

Other suggestions consisted of integrating themes across perspectives and presentations. For example, a Division representative could speak about the goals and objectives of the Division and an outside partner (i.e., academic and NCBDDD partners, Cooperative Agreement) could provide an outcome perspective. Jeremy S., Serena L., Maura A. will work with Barbara K. on determining the speakers, topics and advertising. If anyone from the Partners Group has worked with a specific Hill staffer or would like to work with one in the near future, this would be a good way to target key Congressional staff and to encourage them to attend.

Another suggestion was to send Hill staff to meet directly with Dr. Cordero at NCBDDD in late May (possibly Memorial weekend) to further inform and discuss the overall purpose and goals of the Center.

Lastly, the luncheon may cost approximately \$15 per person for a briefing with 75-100 people, totaling approximately \$1200-\$1500. All catering for events done on the Hill must be by catering companies run out of the House or Senate. Also, an alternative lunch menu (no products with wheat or other leavening) was discussed and will be provided in observance of the Jewish holiday. It was suggested that maybe 2-3 organizations could take on the major financial burden to sponsor the event. Healthy Mothers Healthy Babies (HMHB) has already shown an interest in providing financial support, as well as American College of Obstetrics and Gynecology (ACOG). Barbara K. will be working with HMHB staff on co-sponsoring the event. After the financial letter of support is reviewed by the Executive Committee, it will be sent out to the Partners Group and an electronic invoice will be sent after confirmation of support. This is an important step for the EPG to take in building cash reserves for future activities.

#### ***Update on NCBDDD 2004 Conference – July 26-28, 2004***

##### **Exhibits**

Barbara K. has already sent out exhibit information on how to exhibit to the Partners Group and will send out reminders of the deadline. Also, she needs to know how many

Partners will be exhibiting and will send out another email to confirm participation. Everyone is encouraged to exhibit.

#### Invitation for Hill Staff

Barbara K. discussed the possibility of announcing a trip to the CDC for a tour. It can be combined with a big roll out at the CDC such as the Futures Initiative. The timing is key and specific Hill staffers will need to be identified. This will be an ongoing topic.

#### Awards

Barbara K. sent the National Birth Defects Prevention Network's Godfrey P. Oakley, Jr. Award nomination information to the Executive Committee. The Executive Committee reviewed the nomination form and decided that the criteria of the award will be based on an individual(s) who has made significant contributions to the field of birth defects and DD and to recognize truly outstanding performance. The award will not necessarily be given every year. Additional awards can be added in future years. Also, it was decided that the awards should be held at the Awards Luncheon because it will have greater visibility and participation. The other alternative is to have the awards at the Hill event. This topic will need further discussion. George J., Barbara K., and Clark R. will further work on developing the criteria of the award.

#### National Meeting Symposium

Barbara K's submission was accepted with the possibility of merging three other submissions that were also accepted. The symposium is entitled, "Advancing the Mission of NCBDDD through Partnerships" and she is still working on identifying speakers. The speakers may include congressional staffers.

#### *Wrap Up*

There will be a separate call with Serena L., Maura A., Jeremy S., and George J. to discuss budget and appropriations and advocacy work of the EPG in which the larger Group may be invited to participate. The date and time is to be determined.

Meeting adjourned at 2:41

**\*The next meeting of the EPG and the Executive Committee has been scheduled for Friday, May 7<sup>th</sup> at 1:30pm (EST) – open to all EPG members and potential members.**